

Current Respite Care Arrangements

Submission

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Aged Care Funding Authority

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ABOUT FECCA

The Federation of Ethnic Communities' Councils of Australia (FECCA) is the national peak body representing Australia's culturally and linguistically diverse (CALD) communities and their organisations. FECCA provides advocacy, develops policy and promotes issues on behalf of its constituency to Government and the broader community. FECCA supports multiculturalism, community harmony, social justice and the rejection of all forms of discrimination and racism so as to build a productive and culturally rich Australian society. FECCA's policies are developed around the concepts of empowerment and inclusion and are formulated with the common good of all Australians in mind.

FECCA has had a longstanding presence in policy and systemic advocacy on ageing and aged care issues for CALD Australians. FECCA is the leading stakeholder in CALD ageing and aged care policy, and has been a significant contributor to a range of collaborations, including the National Aged Care Alliance, and partnerships with other peak bodies, to achieve the inclusion and empowerment of older CALD Australians, their carers, and CALD people who work in the aged care industry.¹ FECCA undertook the consultations to inform the *National Ageing and Aged Care Strategy for People from CALD backgrounds*² and was a member of its implementation committee. Currently, FECCA is represented on the Aged Care Sector Committee Diversity Sub-Group where it is working collaboratively with the Department of Health in developing and implementing the Diversity Framework.

FECCA wishes to thank the Aged Care Funding Authority for the opportunity to input into the consultation process and gives consent for this submission to be published in whole or in part.

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¹ FECCA's 2020 Vision for Older CALD Australians, 2015, <http://fecca.org.au/wp-content/uploads/2015/11/FECCA2020Vision.pdf>

² Commonwealth of Australia, *National Ageing and Aged Care Strategy for People from CALD backgrounds*, 2015

Current Respite Care Arrangements

FECCA understands that the Aged Care Funding Authority is seeking views on the increasing use of residential respite care and the appropriateness of the current arrangements under several items which have been highlighted in the consultation paper. FECCA seeks to comment on several of the items, including;

1. The process for applying for and seeking access to respite care;
2. Whether the current system for the allocation of respite bed days to residential care providers impacts the availability and provision of respite care;
3. Impact of the current arrangement on equity of access for respite care recipients, including access in an emergency, or to residential respite for periods of less than one week;
4. Any unintended impacts or consequences of the current arrangements supporting access to residential respite care.

BACKGROUND

The Federation of Ethnic Communities' Councils of Australia is represented on the Aged Care Sector Committee's Diversity Sub Group. This committee is currently tasked with developing an action plan for culturally and linguistically diverse (CALD) older people to access aged care services that meet their needs and expectations. It also developed the Aged Care Diversity Framework launched by Minister Wyatt in December 2017. The vision of the framework is that, ***All older people experience a high quality aged care system that ensures equitable access and outcomes and embraces their diverse characteristics and life experiences.***³ Respite is an integral component of the aged care system, which delivers much needed benefits to alleviate carer stress.

To inform the development of the forthcoming CALD action plan, FECCA undertook a national consultation series, through which it employed several methodologies to inform its research, including linking with CALD consumers through consultations and also offering an online survey which posed a range of questions to consumers and providers. In designing the survey, FECCA was seeking feedback in a number of areas such as access to aged care services and supports, respectful and inclusive services and how the aged care system can be more flexible and proactive. FECCA received a number of responses which related to the provision and access of respite services and will highlight the responses throughout this submission. The responses are current and are reflections of the aged care environment that people from CALD backgrounds face when trying to access services to relieve the pressure of caring for someone with vulnerabilities.

Additionally, Australia's aged care system is evolving to offer increased choice and control for consumers. In this regard it is imperative that the process for applying and seeking access to respite care is flexible enough to allow the consumer (and their carers, representatives and family members) to access respite care when it is required. It is well understood the valuable benefits to all parties involved in the care of the older person in the area of respite care. Access to respite services can greatly alleviate carer fatigue and stress and restores the identity of the care recipient by

³ Australian Government, Department of Health, *Aged Care Diversity Framework*, Aged Care Sector Committee Diversity Sub Group, December 2017, available at https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/04_2018/aged_care_diversity_framework.pdf

assisting to maintain their sense of self, removed from their routine care environment where they may be feel dependent solely on one person, or a team of carers in their familiar environment.

The process for applying for and seeking access to respite care

FECCA is aware that the process for applying and for seeking access to respite services is not user-friendly or accessible for people of CALD background, and does rely on having systems knowledge or having someone to assist with navigating the process. People who are faced with barriers of access due to lack of English language proficiency are further disadvantaged as there is a lack of information in language to inform CALD consumers and their carers of the services available for respite. Also, for some people of CALD background, it is not culturally appropriate to place loved ones into care, as it is seen as the domain of the family to provide all levels of care. However, this is not always tenable, as caring for a vulnerable person can be demanding and assisted by the ability to access suitable respite services. The allocation of 63 respite days per financial year in a residential facility is not well understood amongst CALD populations, particularly as this information is not freely available in translated form.

Whether the current system for the allocation of respite bed days to residential care providers impacts the availability and provision of respite care

FECCA is aware that the current system for the allocation of respite bed days does impact the availability and provision of respite care as this system can be abused by some participants in the system. An example of this is utilising respite bed days to assist in final decision making of residential facility and also utilised as a waiting period for financial preparation purposes (disbursement of funds to furnish Refundable Accommodation Deposits) for entry into residential aged care.

The legislated review of aged care also mentions this anomaly in its review of respite care.⁴ However, the review was unsure of the extent of this issue and places the pressure on respite services on the increase of the number of people accessing residential aged care.

When FECCA addressed the area of flexible and proactive aged care services in its recent national online survey, it received responses directed towards the lack of flexibility in respite services. This question was asked of both consumers and providers of aged care. FECCA would like to share some of the responses, specifically in response to the question posed;

“How can the aged care system be more proactive and flexible?”

Use of interpreters, culturally sensitive (sic) workforce, more **respite** care to enable families who do care for their elderly to have a break, My Aged Care Portal needs complete overhaul..their privacy provisions actively discriminate against those of CALD background as does their contact and engagement processes (cold calling with no interpreters...letters all in English).⁵

Through broad consultation, such as this survey, and analysis and implementation of priority recommendations that do not require lengthy and time consuming assessment (which can be a barrier to service access) and increased access to flexible services. E.g for residential **respite** many providers require booking in 2 week blocks and often several weeks/months in advance. This does not provide proactive or flexible solution to an older person or their caring family needs.⁶

⁴ Department of Health, *Legislated Review of Aged Care 2017*, p. 59.

⁵ FECCA Aged Care Diversity Framework Survey (Provider) Participant # 106

⁶ FECCA Aged Care Diversity Framework Survey (Provider) Participant #260

Impact of the current arrangement on equity of access for respite care recipients, including access in an emergency, or to residential respite for periods of less than one week

The responses from the online surveys included feedback around respite services, when responding to a question on experiences as a recipient of aged care services.

The information provided to us prior to signing contract with the aged care facility (for **respite** services) was misleading. It was only after formal complaint and a number of verbal complaints that the facility started to work on the issue.⁷

Of particular frustration to consumers is the lack of knowledge of the respite process, as mentioned in the background section, which is not easily understood by people who have not engaged with the aged care system previously and/or are novices to the act of providing care. This is seen in the following responses;

My wife had to go to **respite** – I didn't understand the process (sic) and was just given pages and pages of forms to fill in. They weren't explained and I was very stressed as my wife was unwell.⁸

Also;

All service providers operate differently so there's a learning curve. You have to introduce new carers and show them the ropes fairly frequently. Service providers should hand over guidelines of what care recipients should expect (eg what they will do in the house, what they will check ie safety standards). There are no carer organisations that cater for working carers where I live. I have asked so many people about how to undertake future planning and noone has given any useful information. My mother won't go to **respite** and there is noone she can talk to who can earn her trust to persuade her to try it. The MyAgedCare website is not particularly helpful.⁹

And,

My requests for **respite** are unusual so it can be difficult to get the right type of service.¹⁰

In response to the FECCA survey;

“How do we better serve CALD older people who need to access emergency aged care or healthcare?”, respondents addressed the needs for provision of emergency beds specifically for respite purposes with the following responses:

Provision for reserved emergency **respite** beds.¹¹

Have more specific centres just for **respite**.¹²

Difficult with the noted reduction in **respite** care beds available across the sector for any person.¹³

Furthermore, the FECCA survey asked the question;

“What needs to be done for them (CALD groups) to have equal access to services as other groups”

⁷ FECCA Aged Care Diversity Framework Survey (Consumer) #80

⁸ FECCA Aged Care Diversity Framework Survey (Consumer) #149

⁹ FECCA Aged Care Diversity Framework Survey (Consumer) #67

¹⁰ FECCA Aged Care Diversity Framework Survey (Consumer) #75

¹¹ FECCA Aged Care Diversity Framework Survey (Provider) #11

¹² FECCA Aged Care Diversity Framework Survey (Provider) #81

¹³ FECCA Aged Care Diversity Framework Survey (Provider) #132

be more compassion, understanding, meet their needs, do what they need not what is best for you, don't make promises if you can't follow up on them. If they are on a package and they just need transport to the doctor, provide just that, don't provide **respite** if they don't need don't force on them. just listen to the customer, not the family member, sometimes family feel guilty and they will organise services what they think is the best for their loved ones, but always have a professional interpreter there for the customer. Listen to them.¹⁴

Responses to the survey also were clearly in support of not only providing respite facilities, but to service them in an inclusive and respectful way for people of diverse backgrounds. It is one thing to provide the service, however, just as important is to provide a service which acknowledges and respects people who are from diverse backgrounds, including CALD.

Have interpreters (sic) in Emergency departments, access to interpreters in residential care and **respite** facilities (sic), plan for emergencies before they occur, have skilled case managers in Home Care packages who can do this with clients and families.¹⁵

Any unintended impacts or consequences of the current arrangements supporting access to residential respite care.

As Australia experiences increases in the age of the population, it must reflect on the needs of the older cohorts of older people living in regional areas. Older people tend to have higher levels of representation as they remain living in these areas, unlike younger aged cohorts who tend to relocate to urban areas for employment and study options. Therefore, it seems to be the case that there are issues emerging surrounding the access to residential respite care in regional (rural and remote) areas. When FECCA posed the question around being valued and respected as a recipient of aged care services in its recent national online survey, the responses did encompass reference to respite care, such as;

No [I don't feel valued and respected] because of a complete lack of **respite** for carers in rural Australia.¹⁶

Accessibility of respite care is an important issue which aligns with value and respect of the consumer perspective. Value and respect both as a consumer of aged care and a carer where the benefits of respite care should not be underestimated and should be supported by proactive policy directions which address the issue of demand and supply. As seen in the commentary below, caring should be seen as a community responsibility.

Obviously language, distance from family and community required for residential services, re-imagining alternate to **respite** care so it provides flexible support for families to maintain their caring role, lack of knowledge about what is available - service costs, location, plus acknowledged lack of community language speaking paid care workers, and cultural belief that caring is a family and community responsibility.¹⁷

FECCA is aware of the enormous contribution to respite services by CHSP providers and the importance of continuing this particular service aspect. The CHSP program provides flexible options for carers and consumers of aged care, and in particular suits the consumer from CALD background as they often are able to attain support from bilingual and bicultural workers working within the organisation. In respect of this, FECCA supports the submission made by the Multicultural Communities' Council of Illawarra, which is a leading provider of CHSP –funded programs in the Illawarra-Shoalhaven area of NSW which has a significant CALD population.

¹⁴ FECCA Aged Care Diversity Framework Survey (Provider) #34

¹⁵ FECCA Aged Care Diversity Framework Survey (Provider) #156

¹⁶ FECCA Aged Care Diversity Framework Survey (Consumer) #58

¹⁷ FECCA Aged Care Diversity Framework Survey(Provider) #260